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Playing a Part in Research? University Students' Attitudes to Direct-To-Consumer Genomics

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Key Words

Direct-to-consumer genomics · Ethical aspects · Ethics of genetic research · Genetic testing policy · Genomics · Personalized medicine · Privacy

Abstract

Aims: This study examined the attitudes of 1,146 Swiss University students to direct-to-consumer (DTC) genomic testing and to genomic research participation. ***Methods:*** Data were collected through a self-completion online questionnaire by students from 2 higher education institutions in Zurich, Switzerland. The survey aimed to capture motivation for undergoing or refraining from genomic testing, reactions to mock genetic risk results, and views about contributing data to scientific research. Descriptive and inferential statistics were used for the analysis. ***Results:*** A total of 1.5% of the students had undergone testing. Most respondents were studying natural sciences and were interested in undergoing DTC genomic testing. The main motive was to contribute their data to scientific research, followed closely by their interest to find out disease risks and personal traits. Overall, 41% of the respondents were not interested in DTC tests. The primary reasons were concerns about receiving potentially worrying results. There was a significant correlation between studying natural sciences, as opposed to the humanities, and interest in undergoing testing. Male respondents were more interested in testing compared to females. There was a strong interest in genetic research participation and notably limited privacy concerns. ***Conclusion:*** Although 59% of the respondents were interested in DTC genomic testing, they were not likely to be affected by them or act upon them. This raises questions about concerns relating to potential risks of DTC genomics users and users' understanding of genetic information including their awareness of privacy risks. Furthermore, the strong interest in genetic research participation signals an underexplored personal utility of genomic testing which needs to be both better understood and better harnessed.

Introduction

Genetic testing outside the standard clinical setting has been available to consumers for over a decade. Several companies operating in many countries began by offering mostly single nucleotide polymorphism (SNP) analysis from which various kinds of personal genomic information is generated. Such companies usually offer a combination of the following services to their customers: information about the presence/absence of certain genet-

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ic traits, disease risk probability, ancestry, and some pharmacogenomic information. Most companies operate on online interfaces, and initially they employed the so-called direct-to-consumer (DTC) approach whereby users can order the test online and receive their results directly without the mediation of health professionals. We can refer to this as the pure DTC genomics model. This approach hardly comprises the representative model in the current phase of commercial personal genomics, yet it is the one that has sparked the most excitement and debate. Currently, a number of different models are in operation, whereby health professionals are involved to various degrees. Commercial personal genomics has 'reinvented' itself in a number of ways [1], probably partly in response to the controversy that the pure DTC model generated amongst regulators, scientists, bioethicists, and the lay press, but also because the uptake of such services has to date been limited [2]. 'Beyond-the-clinic' genomics is a more accurate term, capturing the variety of practices currently available while focusing on their key shared feature, namely, that they take place beyond the standard clinical setting [3].

The debate about the risks and benefits of DTC genomics focused heavily on arguments about the scientific validity and clinical utility of the results, the burden of genetic information to those faced with probabilistic data as well as concerns about genetic privacy. Proponents of DTC genomics services argued about the rights of individuals to freely access their genetic information, the empowering potential of taking action in relation to one's own health, other personal utilities such as increasing genetic literacy, participating in research, and contributing to the advancement of scientific knowledge [4]. However, the predominant argument made by those opposing DTC genomics services, which was also pre-eminent in the regulatory debates, concerned the risk of harm to the consumers. In the course of the debates that unfolded in the USA [5] and Europe [6], a number of assumptions were made about the prospective users, especially in regard to their attitudes about, and expectations of, such services as well as their overall willingness to use them. Recently, the US Food and Drug Administration issued a cease and desist letter to the leading DTC genomics company 23andMe. While it cited the company's failure to comply with FDA requirements, it also referenced the risks posed to consumers by the use of genomic information that they received from the company [7]. It is not uncommon to hypothesize about potential risks of emerging technologies [8]. Yet, if we are to understand and adequately respond to this 'disruptive innovation' in genetic testing, we need a more systematic assessment of how individuals actually view such options and what is the nature of their expectations and experiences with such testing. Such an assessment will be valuable for the discourse about providing appropriate policy frameworks for such services.

A number of studies have sought to better understand actual and prospective DTC genomics users [9, 10]. While some patterns eventually begin to emerge, i.e. in terms of users' motivation, experience with test results, action taken on the basis of such results, and attitudes about test-taking, empirical data have remained limited. Furthermore, only a few empirical studies have been conducted outside North America. DTC genomics services are primarily offered online, easily crossing national borders and being available within a global market. It is, therefore, important to explore users' attitudes and experiences beyond the Anglo-American context as the different cultural responses to genetics, privacy protections, and health care access are likely to produce diverse user profiles and will likely affect the risk-benefit ratios associated with DTC genomics. We have previously reported on an exploratory study of attitudes, motivation, and experiences of Swiss users, specifically users of the commercial genetic testing provider 23andMe [11]. Our findings suggested that the users in the study, mostly life scientists, were primarily driven by curiosity and had an overall positive testing experience. The qualitative analysis revealed a strong interest in undergoing DTC genomic testing also as a means of participating in scientific research. We attributed this interest to the educational background of the study population which included a significant number of researchers. Based on these finding, we set out to conduct a more comprehensive study with a much larger sample that targeted not only users but also those with demographic characteristics likely to be shared by prospective users (higher educational level, internet users, young). Our aim was to further explore motivation in relation to such testing, including reasons for refraining from testing and possible reactions to disease risk probabilities. Moreover, given that our previous study as well as other studies has identified research participation as a significant personal utility of personal genomic testing, we wanted to further test the validity of this finding.

The Swiss Context

The legal environment for DTC genomics in Switzerland is strictly regulated: Swiss law prohibits genetic and genomic testing that is not prescribed by a physician for

a medical indication [12]. Therefore, companies are not allowed to offer such services from Swiss territory. This law, does not prohibit residents from purchasing such services abroad, i.e. online. The Swiss Ministry of Health, however, has produced a public information leaflet recommending Swiss residents to refrain from online genetic tests due to concerns about their quality and concerns about data privacy. An independent expert advisory body, the Expert Commission on Human Genetic Testing (Expertenkommission für Genetische Untersuchungen beim Menschen (GUMEK)), is appointed by the Ministry to provide expert opinion on issues related to human genetics.

Over the last 2 years, there has been considerable debate about the issue of personal genomics in Switzerland, particularly in the German-speaking part of the country. Several national organizations and academic institutions have developed a strong interest in personalized medicine, nominating it as a research priority area. Against this background, the Swiss Academy of Medical Sciences has issued an opinion paper on the potential and challenges of personalized medicine dedicating a significant section of it on the problems presented by DTC genomics services [13]. The Swiss Technology Assessment Agency has recently completed a study on personalized medicine, including substantial reference to DTC genomics [14]. Finally, at the request of the Ministry of Health, GUMEK has prepared a series of recommendations for the reform of the existing genetic testing law. The suggested reforms aim to update the law in light of developments such as next-generation sequencing, the new challenges of informed consent and counseling in the context of the anticipated data influx, quality control issues, laboratory certification, and genetic data protection.

The proposed reform specifically addresses the issue of DTC genomic testing [15]. GUMEK argues that a pragmatic approach is needed in dealing with commercial entities providing personal genomics services outside the clinical setting. Although it raises serious concerns about DTC genomics and highlights the risks posed to consumers, it admits that maintaining the prohibition of such services does not advance the protection of citizens, since such products are easily accessible on the global market. The alternative approach they suggest is to allow the provision of DTC genomics services in Switzerland under a number of well-controlled conditions. These include a specific list (negative list) of which types of tests cannot be offered, i.e. tests for carrier status of recessive diseases, for monogenic diseases, for disease predisposition of relevant penetrance, and for structural chromosomal aberrations [15, pp. 32–33]. Other conditions include laboratory certification, prohibition of testing of third parties and minors including punitive measures extending in such cases to consumers, not only to service providers (for example in the testing of minors, the adults who submitted the sample would also face charges). Although it is yet to be given legal force, this in an important development, signaling a departure from a regime of strict prohibition and so making it possible for DTC genomics companies to emerge in Switzerland. It is therefore of particular importance to understand potential users' attitudes towards such testing.

Methodology

This study is a survey of attitudes to DTC genomics amongst a large sample of students in the Swiss Federal Institute of Technology (ETH) and the University of Zurich in Switzerland. All participants in this study resided in Switzerland where both public and private health expenditure are comparatively high and health insurance coverage is universal. We conducted an online anonymous survey in 2 sessions between May and June 2013. Upon registration in the above institutions, students can indicate whether they are interested in receiving invitations for online surveys via e-mail. The list of e-mails is maintained by the University administration which distributes survey invitations. An e-mail invitation was sent via this office to undergraduate, bachelor, master as well as PhD students explaining the goal of the study and including the link to a multimedia presentation of internet-based genomic testing and a self-completion questionnaire in German. Permission from the research ethics review committee of the canton of Zurich was requested and received.

The multimedia file included a black-and-white animation and text describing internet-based genomic testing without an audio element. It was developed in collaboration with the Information Technology group of the University of Zurich and was reviewed for content, design, and presentation by experts in genetics, psychology, social science, medicine, law, ethics, and information technology. The survey was developed on the surveymonkey.com platform. We designed the questionnaire on the basis of our previous study and after reviewing similar questionnaires of other published studies [16–18]. Our survey instruments were also reviewed by an internal group and were pre-tested. Adjustments were made, and the final questionnaire included 31 multiple-choice and 7-point Likert scale questions. Questions were intended to capture motivation for testing and reactions to test results. Furthermore, we included a set of questions aimed at exploring the relationship between genetic testing and research participation. We hypothesized that the majority of our respondents are unlikely to have had real experience, and thus we asked participants to imagine the possibility of a DTC genomic test and what would be their likely motives for either undergoing testing or refraining from it. Demographic data including gender, year of birth, and study subject were also collected (table 1).

We conducted descriptive statistical analysis using SPSS Statistics 20.0. complemented by inferential statistics. More specifically,

Table 1. Demographics of the respondents (n = 1,146)

Mean age, years	25
Gender, n	
Females	564
Males	576
Study subject, n	
Natural sciences/engineering	881
Humanities	182
Medicine	45

we conducted Pearson's χ^2 tests to establish associations between attitudes to DTC genomics and religiosity, academic background, gender, degree of concern over personal health, and views on gene versus environment effects on health. Cramer's V was performed to test the strength of association between those categorical variables. The 7-point-Likert scale scores were split into groups which were then compared on different measures with a Pearson's χ^2 test. Significance was accepted at a $p < 0.05$ level. We conducted qualitative analysis of the open-ended questions. Answers were post-coded, but findings are limited as only a small number of responses was available.

Results

A total of 1,146 respondents filled out the survey, representing a response rate of 5.6%. This is within the typical response rate for online surveys administered through the University mailing system. Gender was equally represented in the respondents (50.5% male and 49.5% female students). Our cohort was young, with 75% of all participants between 19–26 years of age. Most students who responded to the survey studied natural sciences (table 1). The heavier representation of natural sciences can be partly explained by the fact that the larger number of respondents came from the ETH which offers natural science and engineering degrees only. Although we did not collect data on nationality, we know that all respondents are residents in Switzerland. In terms of non-Swiss students, the University of Zurich comprises 12% at the bachelor level, 18% at the masters level, and 38% at the doctoral level (numbers of 2012) [19]. In the case of the ETH Zurich, 19.6% of all students at the bachelor level are non-Swiss as well as 37.9% at the masters level and 66.7% at the doctoral level (numbers from 2012) [20].

Approximately two-thirds of the respondents (65.7%) were already aware of internet-based DTC genomics. Humanities students were less likely to have heard of DTC genomics before the survey compared to natural science/engineering students (χ^2 (2, n = 1,107) = 22.782, p = 0.000). The majority ranked their concern about their own health in the middle (mean = 4.3) of a 7-point Likert scale ranging from 1 (not at all) to 7 (very much). Only a small percentage (10.95%, mean = 2) agreed that religion plays a substantial role in their life, and when considering to what extent genes or environment affect health, the majority of the respondents placed it in the middle of 7-point Likert scale (mean = 4.3), representing a mix of both.

Only a very small number of respondents (1.5%, n = 17) had personal experience with DTC genomics. The majority of them studied natural science/engineering and medicine. The primary reasons for having had a test were an interest in personal traits, ancestry, and a general interest in genetics. The majority of these test takers (86.7%) contributed their data to scientific research, and none regretted having undergone testing. Answers to the open question about why they did not regret testing included: usefulness of information about drug sensitivity and health risk information.

From the remaining respondents who did not have actual experience with DTC genomics, about 59% were interested in undergoing such a test. Table 2 shows the respondents' motives ranked by the number of times each reason was chosen. The main motive for undergoing testing was willingness to share the data with the scientific community, followed by an interest in finding out about disease risk and personal traits. About 41% of the respondents were not interested in undergoing DTC genomic testing. The most selected reasons for this were concerns about dealing with the results and concerns about the low validity and utility of such tests (table 2).

We explored the relationship between interest in testing and study subject, gender, religiosity, concerns about own health, views about the environment/genes health effects. We identified a significant correlation between studying natural sciences/engineering and interest in undergoing DTC genomic testing as compared with studying humanities (χ^2 (2, n = 1,092) = 7.140, p = 0.028). High religiosity was negatively associated with willingness to undergo testing (χ^2 (1, n = 1,057) = 35.061, p = 0.000). Similar to other reports, in our sample male respondents were more interested in being tested compared to female respondents (χ^2 (1, n = 1,123) = 16.857, p = 0.000) (table 3) [18, 21, 22]. Furthermore, we found a significant relationship between willingness to contribute genetic data to scientific research and study subject: those studying science/engineering and medicine were more likely to have answered that they would contribute their data compared to those studying humanities (χ^2 (2, n = 906) = 8.890, p = 0.012). While for the former the primary reason

Table 2. Respondents' answers

Response	n	%
Ranked reasons for undergoing DTC genomic testing [a]		
I would like to contribute my genetic data to scientific research	477	72
I would like to know if I am at risk of certain diseases	440	66
I would like to find out about my genetic traits	436	66
I would like to know the risk of my passing on to my children a predisposition to disease	368	56
I would like to know my sensitivity to certain medication	348	52
I would like to find out about my genetic ancestry	332	50
I am interested in genetics in general	315	48
Just for fun	252	38
If I were able to buy the test at low cost	251	38
I was curious about how such a test works	218	33
Ranked reasons for refraining from DTC genomic testing [b]		
I am concerned that the results will worry me	278	60
I do no think the test results are valid	257	56
I do not see any utility in such tests/I am not interested in my genetic profile	209	45
I am concerned about the privacy of my data	202	44
Cost is an obstacle to undergo testing	111	24
I am skeptical about genetic testing in general	67	17
Ranked reasons for not participating in a genetic study in the clinic		
I am concerned that the results will worry me	150	54
Time would be an obstacle to participating	124	45
I am concerned about the privacy of my data	89	32
I am skeptical about genetic testing	56	20
I question the validity of the test	39	14
I am not interested in genetics at all	12	4

[a] Furthermore, a χ^2 test including the categorical variables gender and background was conducted and revealed the following results: females were more likely to be interested in genetics (χ^2 (1, n = 661) = 5.371, p = 0.020), and students from humanities were less likely to be interested in genetics (χ^2 (2, n = 651) = 11.139, p = 0.004) as well as in personal traits (χ^2 (2, n = 651) = 9.006, p = 0.011).

[b] Furthermore, a χ^2 test including the categorical variable gender was conducted and revealed the following result: males were less likely to be concerned about results (χ^2 (1, n = 462) = 13.864, p = 0.000).

for testing was contribution to research, for the latter the primary reason was receiving the genetic information about their personal health risks. We did not observe any significant effects when conducting frequency analysis amongst all categorical variables (gender, background, etc).

Responses to Hypothetical High/Low Genetic Risk of Two Conditions

Participants were asked to react to 2 hypothetical results indicating elevated and decreased risk of colon cancer and obesity (table 4). Respondents could choose multiple reactions from a list of options. We ranked the reactions according to the total number of times they were selected. In the scenario of increased colon cancer risk, the most likely reaction chosen was to take measures to reduce the risk (through screening and lifestyle changes) (n = 605) followed by the option of consulting a medical doctor (n = 577). The third most chosen option was the one suggesting that the results would not have an effect on the recipient due to their highly probabilistic nature (n = 444). The option that results would be alarming was ranked lower (n = 406), and very few indicated that these results are meaningless and would be completely ignored (n = 18). In the case of a decreased colon cancer risk, the option chosen most often was the one suggesting that the results would not have an effect on the recipient due to their highly probabilistic nature (n = 749), followed by the option that the results are reassuring (n = 339).

In the case of an increased risk of obesity (table 4), the most commonly chosen reaction was that of taking measures to decrease risk (through sports, nutrition) (n =

Table 3. Interested in undergoing DTC genomic testing

	Yes, n (%)	No, n (%)	n_{Total}	p value
Gender				
Females	**294 (52.8)**	263 (47.2)		
Males	**367 (64.8)**	199 (35.2)	1,123	0.000
Religion				
Religious	44 (35.2)	**81 (64.8)**		
Not religious	**586 (62.9)**	346 (37.1)	1,057	0.000
Background				
Natural sciences	**536 (61.6)**	334 (38.4)		
Humanities	**93 (52.5)**	85 (47.8)	1,048	0.028
Health Status				
Concerned	**207 (66.1)**	106 (33.9)		
Not concerned	**105 (54.1)**	89 (45.9)	507	0.007

n_{Total} ranges between 507 and 1,123 due to a varying total number of responses. The higher value is indicated in bold, and significance was accepted at $p < 0.05$.

553), followed closely by the option of feeling unaffected due to the highly probabilistic nature of results (n = 505). In the case of a decreased obesity risk scenario (table 4), responses were similar to the decreased colon cancer risk: the option chosen most often was the one suggesting that the results would not have an effect on the recipient due to their highly probabilistic nature (n = 705). The second most chosen option was the one indicating a sense of reassurance about good health (n = 252). In general, when we compared good and bad results (low- and high-risk probability of developing either disease) to primary reactions, we found that good results led to more doubts about the utility of the tests compared to bad ones (χ^2 (1, n = 1,146) = 90.044, p = 0.000). When we compared specific reactions with interest or not in undergoing testing, we found that students who were not interested in DTC genomic testing were more likely to think that results (good or bad) were not valid (for increased colon cancer risk: χ^2 (1, n = 1,128) = 7.301, p = 0.007; for increased obesity risk: χ^2 (1, n = 1,128) = 20.085, p = 0.000; for decreased colon cancer risk: χ^2 (1, n = 1,128) = 29.611, p = 0.000; for decreased obesity risk: χ^2 (1, n = 1,128) = 20.626, p = 0.000). Yet, they were likely to be alarmed by bad results (increased colon cancer risk: χ^2 (1, n = 1,128) = 105.425, p = 0.000; increased obesity risk: χ^2 (1, n = 1,128) = 18.064, p = 0.000) and less likely to be reassured by good results (decreased colon cancer risk: χ^2 (1, n = 1,128) = 10.979, p = 0.001; decreased obesity risk: χ^2 (1, n = 1,128) = 18.760, p = 0.000).

Interest in Participating in a Genetic Study Conducted in a Clinic

Seventy-five percent of the students would participate in a genetic study within a clinical setting (e.g. in a hospital). They would thereby agree to undergo a genetic test and provide information about their health state and lifestyle. The most frequently chosen motive for participation was contributing to scientific progress followed by receiving genetic information about themselves. An open-ended option revealed an additional reason which we had not included, namely financial compensation for participation. Most respondents would like to be informed about their genetic tests results. More than half (54%) would like to receive all results irrespective of whether preventative or curative measures could be taken, while 37% would want to receive results only for conditions that could be prevented or treated. Male students were more likely to want to know all their genetic results (χ^2 (2, n = 842) = 25.784, p = 0.000). Nine percent of respondents wanted to participate in a genetic study conducted in a clinic but without receiving any results. The most frequently chosen reasons by those respondents was their concern that they might receive information that they did not wish to have, and also that they did not know how such results might impact on their families.

One-fourth (25%) of the respondents did not wish to participate in a genetic study in a clinical setting. The main reason for that was concern about receiving genetic results, while the second most important reason was time constraints (table 2; fig. 1). In the open-ended option, respondents provided an additional reason for refraining from testing, i.e. the possible consequences that such information could have on their reproductive choices. To the question of what kind of research institution they would prefer, our respondents were more likely to participate in genetic studies conducted by public institutions (e.g. university hospital) (72.5%) as well as private, non-profit institutions (e.g. Cancer Society) (54.1%). For-profit institutions were not in favor.

Discussion

We found a high level of awareness about DTC genomics in our study population [23–27], something that can be explained by the media attention that this issue has received in the German-speaking part of Switzerland over the last 2 years. In general, most respondents who were interested in DTC genomics had a natural science/engineering background. As other studies have shown, early

Table 4. Hypothetical high/low genetic risk

Response	↑Colon cancer	↓Colon cancer	↑Obesity	↓Obesity
I would take measures to reduce the risk	605		553	–
I would become lax about taking care of my health	–	59	–	120
I would consult a medical doctor	577	45	108	27
I would take note of the results but they would not affect me due to their merely probabilistic nature	444	749	505	705
I would worry about my health	406	–	125	–
I would be reassured about my health	–	339	–	252
I would discuss results with family/friends	221	92	139	75
The results are worthless and I would ignore them	18	65	168	126

adopters are interested in genetics or are in general of a higher educational level. The key reasons for potentially undergoing DTC genomic testing in this study population was the opportunity for research participation as well as receiving information about health and personal traits. These findings are similar to other studies [9], although it is of particular interest that in our sample research participation was highly ranked. The research participation motive was mostly chosen by science/engineering and medical students. Students studying humanities were more motivated by finding out genetic information about themselves. It is likely that students engaging with scientific research (e.g. lab, clinic) might be more aware of the issues around research participation and may feel more inclined to see themselves contributing to such research.

A total of 41% of the students (n = 465) was not interested in undergoing DTC genomic testing. Since many of the empirical studies have focused on collecting data relating to positive motivation to undergo testing, we have less systematic data about why people would refrain from testing. Our findings suggest that students, who are concerned about receiving information they might not want to know or those feeling that they will get worried about their health risks, are less likely to be interested in being tested. One of the common arguments in the debate about DTC genomics is that individuals will receive information that they cannot understand or be able to interpret meaningfully, and that they are, therefore, at risk of psychological harm, distress etc. [16, 21, 28]. Our findings suggest that ordinary deliberation evaluating options precede the decision to undergo a test such as this. It is still possible that individuals, who believe they will not be worried about genetic results, might nonetheless become worried when they actually receive them. However, prevalent generalizations about adverse psychological reactions need to take into account the likelihood that those susceptible to such reactions will choose not to undergo testing. A further observation of interest is that there was no strong association between study subject and reasons for refraining from testing. The concern about confronting genetic information and bad results (high risks) were a primary consideration across all study subjects. Therefore, the concern about dealing with genetic information is probably not necessarily only associated with the absence of a scientific or technical background (or the work-

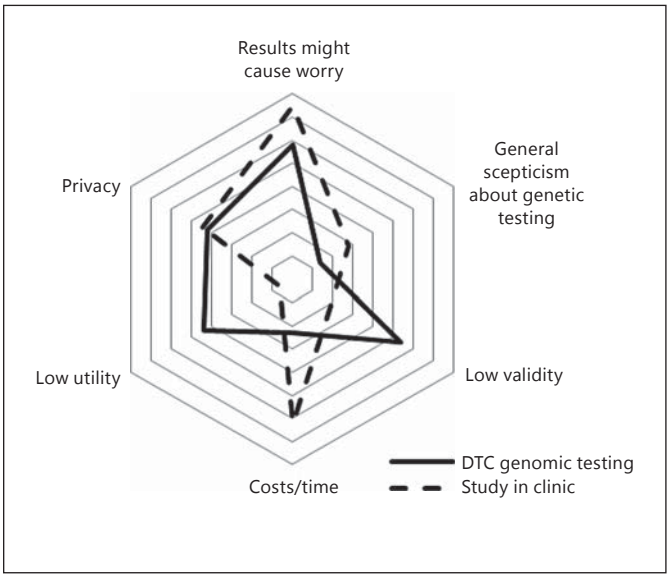

Fig. 1. Comparison of reasons for not undergoing DTC genomic testing vs. not participating in clinical genetic studies. Data has been normalized in order to accommodate for varying total number of times each reason was chosen. Categories have been grouped and slightly renamed.

ings of science phobia) and may be more related to differences in personalities, general life views, and life circumstance that cut across the science/humanities divide.

Reactions to mock results showed that increased colon cancer risk would likely generate more action including involving a medical doctor, while higher obesity risk would not do so to the same extent. Respondents might have considered colon cancer to be more life-threatening than obesity. The fourth most commonly chosen reaction was that results would cause alarm. Further analysis showed that this option was mostly chosen by those students who were not interested in getting tested and who had given as a reason for this their concern of becoming worried by the results. This is a consistent finding, further demonstrating that worrying about results is an important concern but, as described above, one that also causes reservations about undergoing genetic testing in the first place (χ^2 (1, n = 1,146) = 248.972, p = 0.000). Nevertheless, worrying about genetic information is a broader issue that requires further consideration. One question is the extent to which this anxiety is related to perceptions about genetics and its predictive power. Another more intriguing question is whether anxiety is related to the lack of information that is decision-relevant. Can the information that is obtained from testing be put in use when decisions about health, lifestyle, and life in general are made? Future studies should investigate these questions. As Condit [29] has argued, new genetic technologies require that people have 'decision-relevant' understanding of genetics and not merely 'awareness' of it. Furthermore, forms of genetic counseling will also have an important role to play for those who engage with genetic testing.

It is noteworthy that although in the case of high risk regarding both conditions, respondents judged they would take action to reduce risk, in the case of low risk their most likely reaction was that they will feel unaffected due to the results' probabilistic nature. Even lower ranked the option that such results would reassure them of their good health. One likely explanation is that bad news in general tend to have more impact [30], and hence they are more alarming. In the case of good news, other issues surfaced, such as those about the nature of the tests and their low clinical utility. Other studies, however, that have examined experiences of actual test-takers show that users are unlikely to act on the results they receive through DTC testing, even if at the time of testing they intended to act [9, 21]. It is unclear why DTC genomics results do not seem to have either a positive (or negative) effect on actions about health [31]. In our sample, students consistently across the 4 scenarios chose the option that the probabilistic nature of results is such that leaves them unaffected, echoing the low clinical utility argument about DTC genomics. It is worth exploring whether this view of low clinical utility undermines the power of the results in terms of their actionability. In addition, it is worth investigating whether this view of DTC genomics would also prevent or ameliorate concerns about dealing with the results.

A number of studies have shown that DTC genomics users are motivated to undergo testing due to the opportunity for research participation. DTC genomics companies also report a high percentage of their users actually contributing to research by consenting to their data being used for research as well as by actively filling out questionnaires regarding phenotypic and medical history. Elsewhere, we have argued that research participation is an aspect of the personal utility that personal genomics may have for users [11, 32]. However, most of the debate about DTC genomics has focused on the low clinical utility of the tests, leaving the personal utility aspect underexplored. As mentioned above, research participation was a significant motive for our study population, confirming the significance of this utility. We compared this interest in research participation through the DTC path with interest in participating in genomic research at the clinic. Most of our respondents were also interested in participating in genetic research within the clinical setting, and we observed a consistency in this choice amongst those who would participate in DTC genomic testing and research. Most of those interested in participating were also interested in receiving all results.

Students favored to support public, not-for-profit institutions performing genetic research. We did not explore the reasons for this preference in this study. Concerns have been raised in the literature about the risk of damaging research participants' trust when data that have been collected in the name of a collective research project are used for profit making purposes with a limited number of beneficiaries from the profit. When 23andMe acquired its first patent on a method to ascertain susceptibility to Parkinson's disease, outrage was expressed in the blogosphere at the mismatch of motives between users and the company [33, 34]. In our sample, there was a strong preference in favor of the non-profit institutions, suggesting that they are viewed as more likely to promote the common good than outfits which prioritize profit-making. In order to harness the willingness of people to contribute to genetic research, their attitudes to it, their expectations from it, and their assessment of risk and benefits should be better understood [35, 36]. This should

include the relationship between interest in genetic research participation and the type of research institution people consider trustworthy.

Privacy concerns and risks of discrimination were found to be disincentives to genetic testing and genetic research participation in some studies, or at least in studies that specifically investigated the issue of privacy [37]. However, it is notable that privacy concerns, one of the most heavily debated aspects of genetic research, did not rank highly in this study population. This is likely to be explained by several factors. First, the population we studied was young. Young people are often portrayed as less concerned about privacy matters, although such reports tend to be anecdotal. Other studies have shown a disconnect between the privacy young people would have liked to have and the one they end up being offered online. Studies have also shown that younger people tend to have a privacy knowledge gap which may explain why they tend to be less concerned about it [38]. It is plausible that our students had a similar privacy knowledge gap. An alternative explanation may be that given the high level of privacy protection in Switzerland, the students might in general have fewer concerns about suffering privacy harms. It is also possible that, in the case of research, an acceptable trade-off between privacy and utility (in the form of contributing to scientific research) might be at play. Some studies have found that individuals accept such trade-offs because of the value they attributed to research [36, 39]. Finally, another explanation might be the still fairly low predictive power of genetic information which in turn provides relatively limited serious cases for concern where privacy might become an issue. As genetics research progresses and potentially becomes more predictive, and as more controversial traits are explored (e.g. behavioral traits), it is possible that privacy concerns might increase.

Of particular interest were the reasons given by those who were not interested in participating in genetic studies within the clinical context. Here again, the primary reason was concern about confronting genetic information, the same reason that was given for refraining from DTC genomic testing altogether. An almost consistent profile emerges of the student who avoids genetic information irrespective of the context in which such information is generated (fig. 1). Those who are uneasy with genetic information are likely to stay away from this type of information no matter what guarantees are in place or whatever the level of validity or clinical utility of the results might be. By contrast, those who are interested in undergoing genetic tests are also more likely to participate in studies in the clinic (χ^2 (1, n = 1,104) = 190.549, p = 0.000) and willing to be informed about the results (χ^2 (2, n = 831) = 117.728, p = 0.000).

Limitations

Our study is limited as our sample consisted entirely of University students, and our findings are, therefore, not generalizable to the broader population of the same age. Moreover, given that a large number of students who received our e-mail invitation did not respond, we might have a skewed sample representing those who have a preexisting interest in the issue we were investigating. However, studies about DTC genomics have reported that users tend to have a higher educational level, an interest in biology/genetics, and to be internet savvy. All these are characteristics of our respondents. Therefore, our sample resembles the likely user of DTC genomics services. Another limitation of the study is that it is based on hypothetical scenarios, responses to which may differ from actual decisions and experience [38]. However, given that the uptake of DTC genomics is low, at least in most European countries, it is difficult to identify a large sample of people who have had such experience. We argue that empirical data with hypothetical scenarios still provide insights into the motivation and concerns of prospective users and can inform the debate about what risk and benefits users might see in DTC genomics as well as the discussion about appropriate policies.

Conclusions

The emergence of DTC genomics has posed questions about risks and benefits to the consumers and has generated a serious debate. Policy makers in Switzerland and elsewhere are currently deliberating appropriate regulatory frameworks which are further complicated by the fact that such services are offered in online global markets. The FDA's recent move has certainly fueled the debate about how we should handle DTC genomics and highlighted the need to clarify what the risks and benefits of DTC are. However, for a truly informed deliberation, it is imperative to have a better understanding of the consumers' motivations to take up personal genomics services, their expectations from it, and their perceptions of utility. Our study confirms that there is a relatively high interest in DTC genomics at least in this group of young people, despite perceiving such testing as having rather

limited clinical utility. However, a large number of participants was not interested in DTC genomics due to worries about genetic results. The same reason was cited by those who did not want to participate in studies in the clinical context. This finding indicates (a) that as is in other life situations practical deliberation about options precedes choice, and individuals who worry about receiving genetic test results will likely not undergo DTC test, and (b) that concerns about dealing with genetic information is not uncommon and that they can affect interest in genetic testing for research purposes. Notably, concerns about genetic data privacy were low. Concerns about dealing with genetic results and limited interest in privacy issues highlight the need for better and more comprehensive public engagement initiatives specifically addressing younger people. Finally, it is a significant finding that research participation seems to be an important personal utility. This is an underexplored issue that we hope further studies will tackle. Given the increasing need for genetic data for research purposes, it is important to pay attention to the willingness of people to participate in research. If this potential for the common good of research were to be harnessed, appropriate opportunities for participation should be created and necessary protections should be afforded to participants. It is critically important to maintain people's trust and sustain their willingness to be part of the genetic research enterprise.

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